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# The Association Between HIV Disclosure Status and Perceived Barriers to Care Faced by Women Living With HIV: The ELLA Study

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# Conflicts of Interest

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**M Loutfy** has acted as an advisory board member and speaker for AbbVie Inc., Merck, ViiV Healthcare, Gilead Science, and BMS

**M Johnson** is an employee of the Royal Free Hospital NHS Trust; has consultancy agreements with AbbVie, ViiV Healthcare, BHS, and Gilead Sciences; has received payments for lectures from AbbVie, ViiV Healthcare, BHS, and Gilead Sciences; and has received payments from GlaxoSmithKline and MS Pharma for developing educational presentations

**S Walmsley** has served on advisory boards and acted as a speaker for AbbVie, Merck, ViiV, Gilead, Janssen, and BMS

**P Vasquez** has received payments for lectures from AbbVie Inc., ViiV Healthcare, BMS, Merck, Sharp & Dohme, and Gilead Sciences, and has received invitations to attend conferences from AbbVie, ViiV Healthcare, Merck, Sharp & Dohme, and Gilead Sciences

**A Samarina** and **H Hao-Lan** have no conflicts of interest to declare

**M-J Fournelle**, **M Martinez-Tristani**, and **J van Wyk** are employees of AbbVie Inc. and may hold AbbVie stock or options

The authors and AbbVie scientists designed the study and analyzed and interpreted the data. All authors contributed to the development of the content, all authors and AbbVie reviewed and approved the presentation, and the authors maintained control over the final content. Medical writing support was provided by John E. Fincke and Tiffany Brake of Complete Publication Solutions, LLC, Horsham, PA. AbbVie funded the research and medical writing support.

# Background

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## What is known about HIV disclosure and health?

1. HIV status disclosure is associated with improved health outcomes<sup>1</sup>
2. Women are less likely than men to disclose their status<sup>2</sup>
3. Lack of disclosure has been shown to stem from fear of stigma, discrimination, rejection, abandonment, or violence<sup>3</sup>
4. Fear of involuntary disclosure is a barrier to seeking antenatal antiretroviral therapy<sup>3</sup>

1. Chadoir SR, et al. *Soc Sci Med.* 2011;72:1618-1629
2. Hirsch Allen AJ, et al. *AIDS Behav.* 2014;18:1014-1026
3. Duff P, et al. *J Int AIDS Soc.* 2010;13:37

# The ELLA Study

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ELLA was a cross-sectional, non-interventional cohort study across 4 global geographic regions (Latin America, China, Central/ Eastern Europe, and Western Europe/Canada) that assessed global and regional barriers to access to care affecting women living with HIV

## Purpose

In this sub-analysis, we examined the relationship between perceived barriers to care faced by women with HIV and disclosure of HIV status

# Study Population & Design

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- ELLA enrolled women  $\geq 18$  years of age with HIV-1 infection for  $\geq 3$  months
- Women were given the opportunity to participate in the study (non-random sequential sampling frame design) while attending a routine follow-up clinic visit
- Women completed questionnaires at a single time point, including the Barriers to Care Scale (BACS)<sup>1</sup> and the Overall Health Status Assessment
- Sites completed a Data Recording Form for each patient, which included patient demographics, medical history, and HIV infection-related data

1. Heckman TG, et al. *AIDS Care*. 1998;10:365-375

# Study End Point

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- Women completed the self-reported 12-item BACS questionnaire
  - The 12 items: (1) Long distance to medical facilities; (2) Declined direct care to a person with HIV; (3) Lack of trained and competent AIDS health care provider; (4) Lack of transportation; (5) Lack of mental health healthcare provider; (6) Lack of psychosocial support; (7) Community HIV knowledge; (8) Community stigma; (9) Lack of employment opportunities; (10) Lack of supportive work environment; (11) Personal financial resources; (12) Lack of adequate housing
  - For each item, respondents used a 4-point Likert scale (1=No problem at all, 2=Very slight problem, 3=Somewhat of a problem, 4=Major problem) to indicate the extent to which each barrier made it difficult for them to receive the care, services, or opportunities they wished to obtain; scores  $\geq 2$  were considered to be significant
- Women who answered  $\geq 6$  BACS items were included in the analysis and categorized by HIV disclosure status

# Statistics

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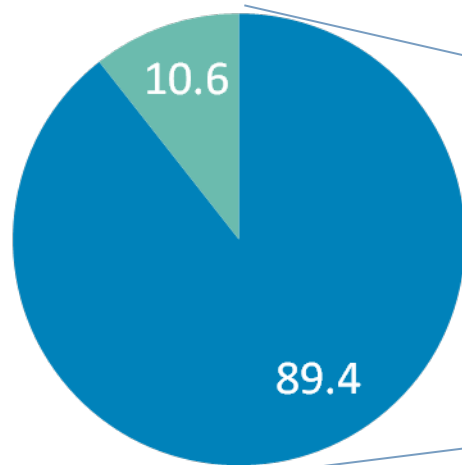
- Correlate of interest = Disclosure - DICHOTOMIZED
  - Not disclosed to anyone outside of the healthcare system
  - **Disclosed to close/intimate relations**
  - **Disclosed to extended relations**
  - **Full disclosure**
- Analyses of interest included the relationship between HIV disclosure status and prevalence and severity scores for individual BACS items (n=12)
- Between-group comparisons were assessed using the Wilcoxon-Mann-Whitney test (for continuous variables) or the chi-square test (for categorical variables)



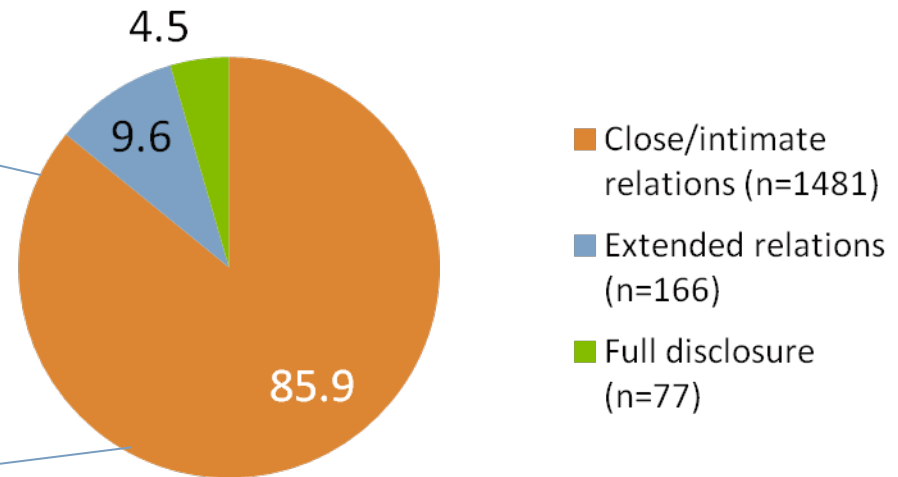
# Results: Disclosure Status

Of 1945 patients enrolled, 1929 were included in the analysis

**Disclosure (N=1929)**



**Extent of Disclosure (N=1724)**



■ Disclosed (n=1724) ■ Not disclosed (n=205)



# Disclosure by Region

Disclosure Type,* n (%)	China (n=120)	Central & Eastern Europe (n=532)	Latin America (n=519)	Western Europe & Canada (n=760)	Total (N=1931)
Not disclosed	35 (29)	39 (7)	35 (7)	96 (13)	205 (11)
Disclosed to close/intimate relations	81 (68)	438 (82)	415 (80)	547 (72)	1481 (77)
Disclosed to extended relations	3 (3)	46 (9)	54 (10)	63 (8)	166 (9)
Full disclosure	1 (1)	9 (2)	15 (3)	52 (7)	77 (4)
Missing	0	0	0	2 (<1)	2 (<1)

\*Percentages may not total 100% because of rounding

# Baseline Demographic Characteristics

Characteristic, n (%) or mean $\pm$ SD	No Disclosure (n=205)	Any Disclosure* (n=1724)	Total (n=1929)	P Value <sup>†</sup>
Age, mean $\pm$ SD	42 $\pm$ 11	40 $\pm$ 11	40 $\pm$ 11	0.0080
Residence				0.7050
Rural	37 (18)	293 (17)	330 (17)	
Urban	168 (82)	1431 (83)	1599 (83)	
Living status				<0.0001
Alone	86 (42)	328 (19)	414 (21)	
With others	52 (25)	397 (23)	449 (23)	
With partner/husband	67 (33)	999 (58)	1066 (55)	
Serodiscordant with partner <sup>‡</sup>	27	486	513	0.0003
Employed	119 (58)	894 (52)	1013 (53)	0.2164
Born in country of residence	139 (68)	1382 (80)	1521 (79)	0.0008
Family/friend support	48 (23)	1111 (64)	1159 (60)	<0.0001

\*Disclosure to close/intimate relations (n=1481), to extended relations (n=166), or full disclosure (n=77).

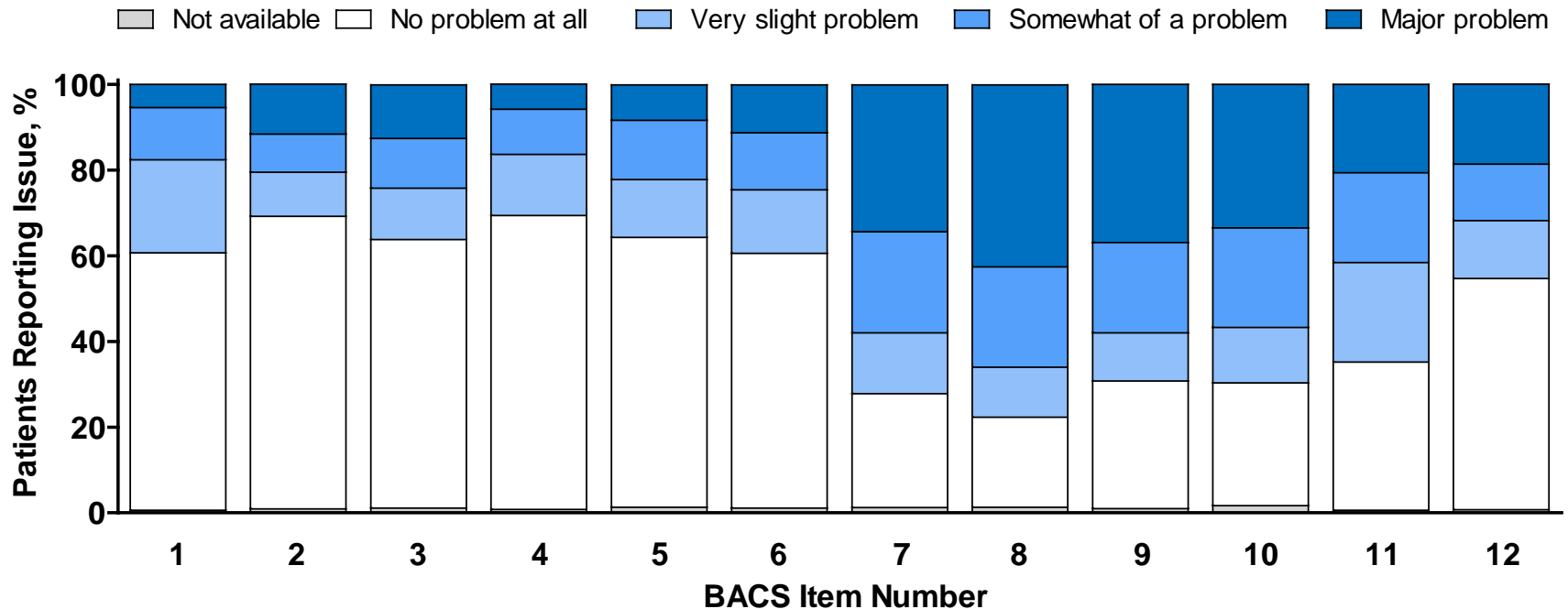
<sup>†</sup>Chi-square (categorical variables) or Wilcoxon-Mann-Whitney (continuous variables) test, disclosed vs non-disclosed.

<sup>‡</sup>For women living with a partner (no disclosure; n=67; disclosure, n=486; total, n=513).

## Baseline Disease Characteristics (cont'd)

Characteristic, n (%) or mean $\pm$ SD	No Disclosure (n=205)	Any Disclosure* (n=1724)	Total (n=1929)	P Value <sup>†</sup>
Time from diagnosis to enrollment, y				0.0215
<1	15 (7)	103 (6)	118 (6)	
1 to 5	78 (38)	538 (31)	616 (32)	
>5 to 10	57 (28)	427 (25)	484 (25)	
>10	46 (22)	587 (34)	633 (33)	
Unknown	9 (4)	69 (4)	78 (4)	
Latest viral load <50 copies/mL	126 (61)	985 (57)	1111 (58)	0.4036
Last recorded CD4+ count, cells/mL	545 $\pm$ 284	539 $\pm$ 284	540 $\pm$ 284	0.9406
Use of antiretroviral therapy				0.1526
Never	20 (10)	136 (8)	156 (8)	
Previous	3 (2)	67 (4)	70 (4)	
Current	182 (89)	1521 (88)	1703 (88)	
Comorbidities >10% in total population				
Anxiety/depression	36 (18)	316 (18)	352 (18)	
Hepatitis C	16 (8)	268 (16)	284 (15)	

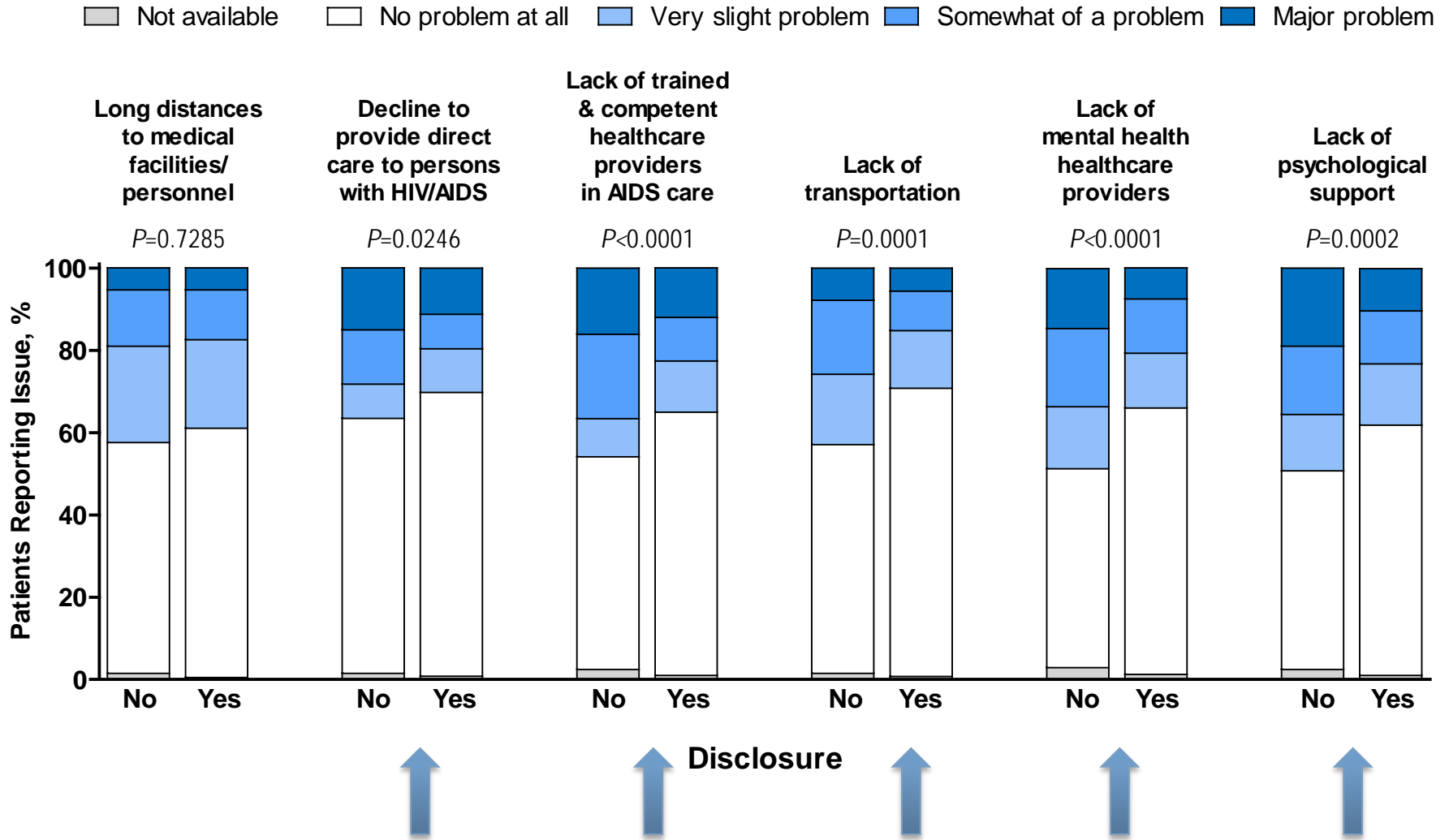
# Overall BACS Prevalence (Global Population)



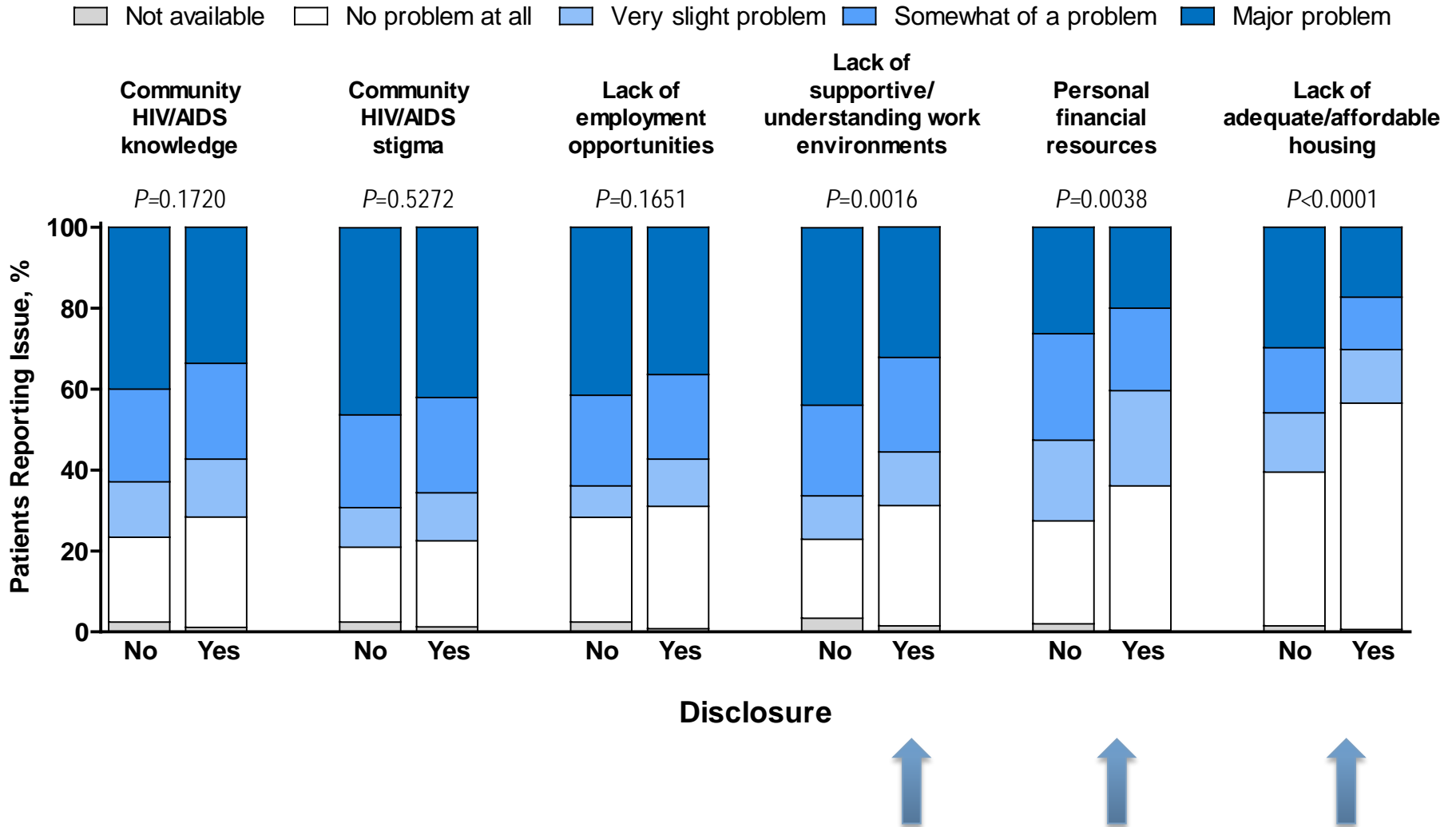
**BACS Item 1: Long distances to medical facilities/personnel**  
**BACS Item 2: Decline to provide direct care to persons with HIV/AIDS**  
**BACS Item 3: Lack of trained & competent healthcare providers in AIDS care**  
**BACS Item 4: Lack of transportation**  
**BACS Item 5: Lack of mental health HCPs**  
**BACS Item 6: Lack of psychological support**

**BACS Item 7: Community HIV/AIDS knowledge**  
**BACS Item 8: Community HIV/AIDS stigma**  
**BACS Item 9: Lack of employment opportunities**  
**BACS Item 10: Lack of supportive/understanding work environments**  
**BACS Item 11: Personal financial resources**  
**BACS Item 12: Lack of adequate/affordable housing**

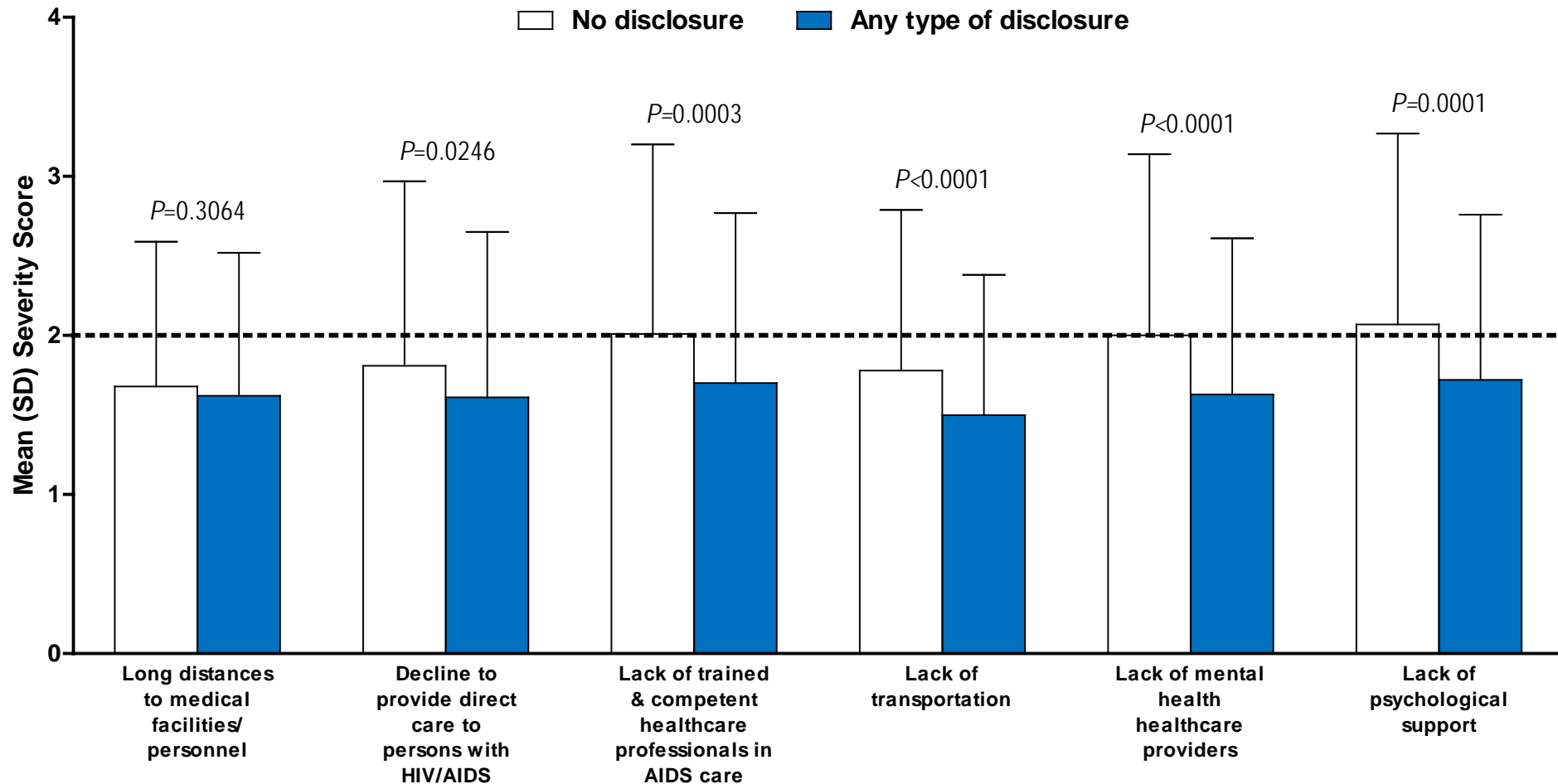
# Prevalence of Barriers to Healthcare



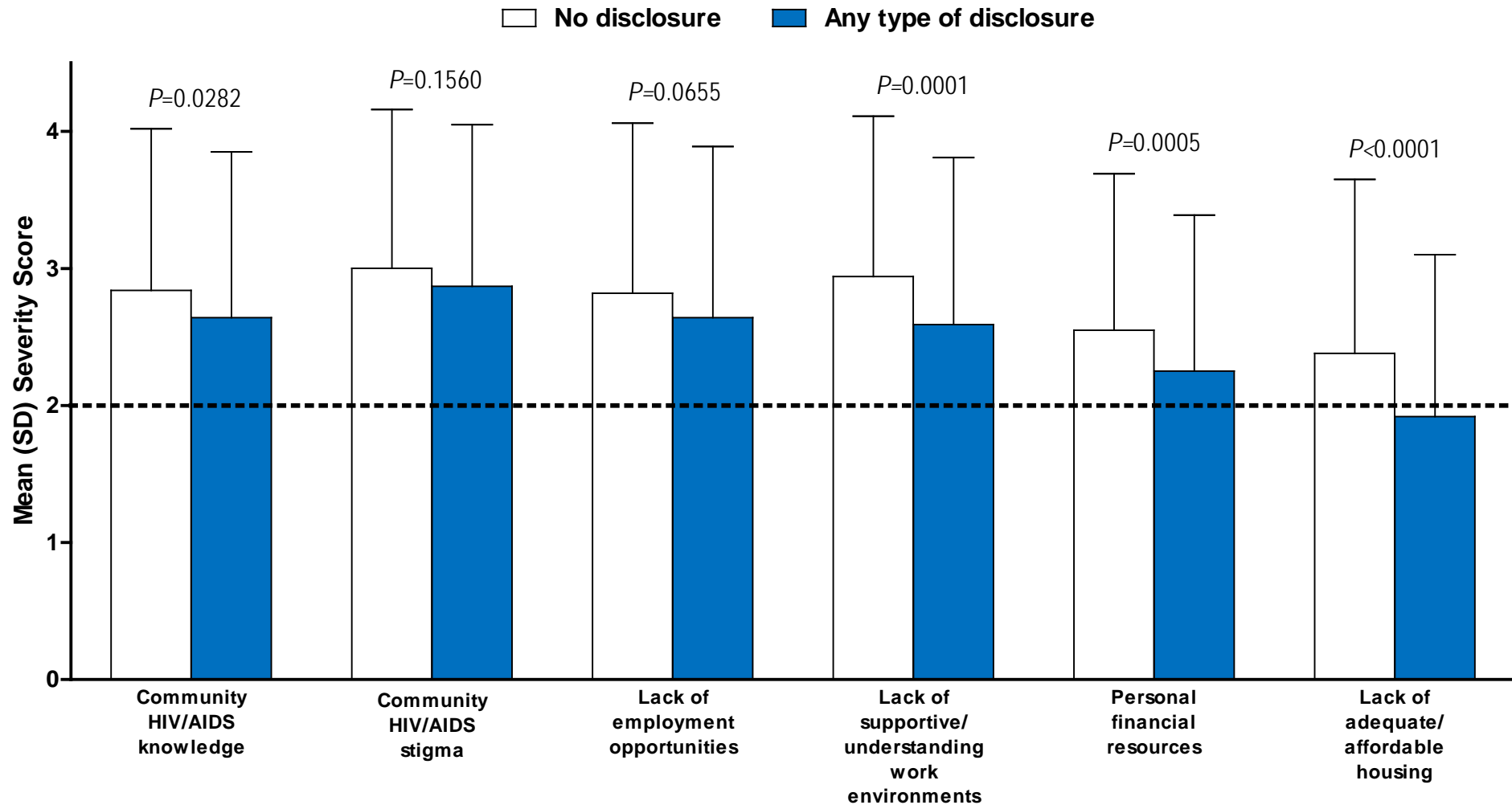
# Prevalence of Barriers to Healthcare (cont'd)



# Problem Severity of BACS Items



# Problem Severity of BACS Items (cont'd)

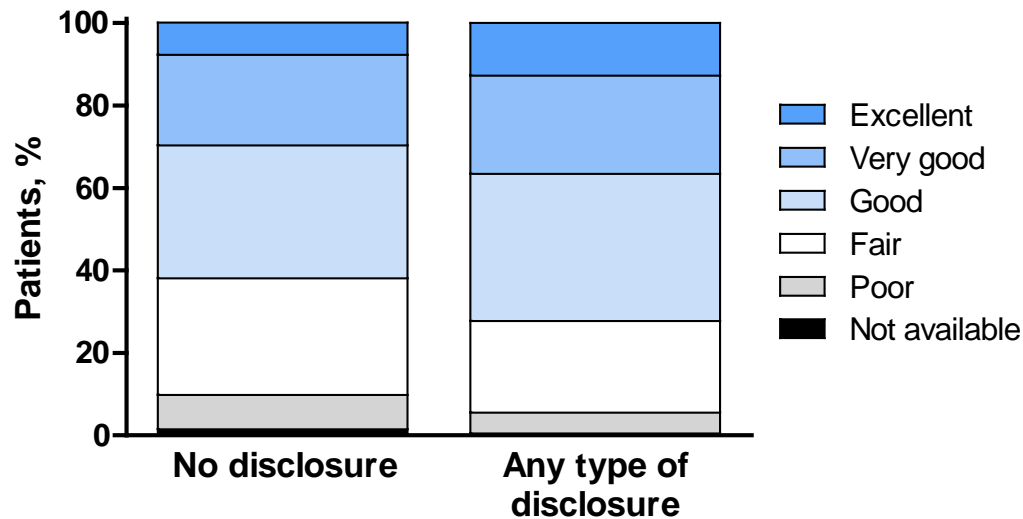




# Preliminary Analysis – Quality of Life

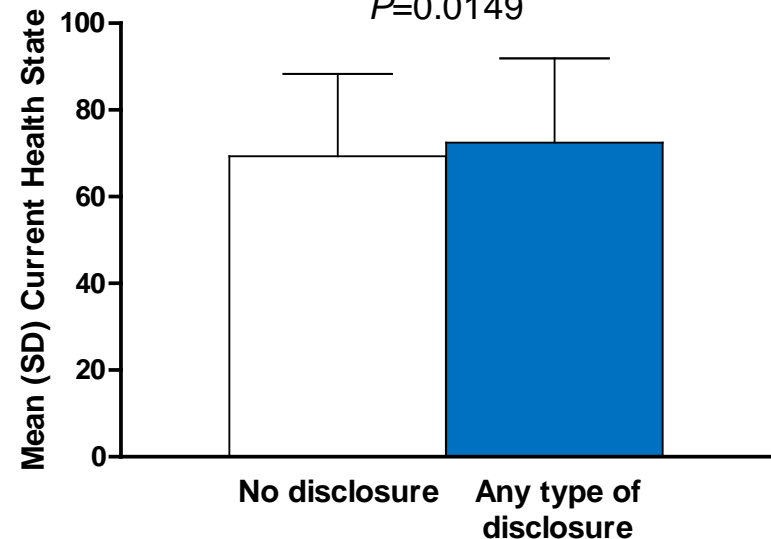
## General Health Questionnaire

$P=0.0226$



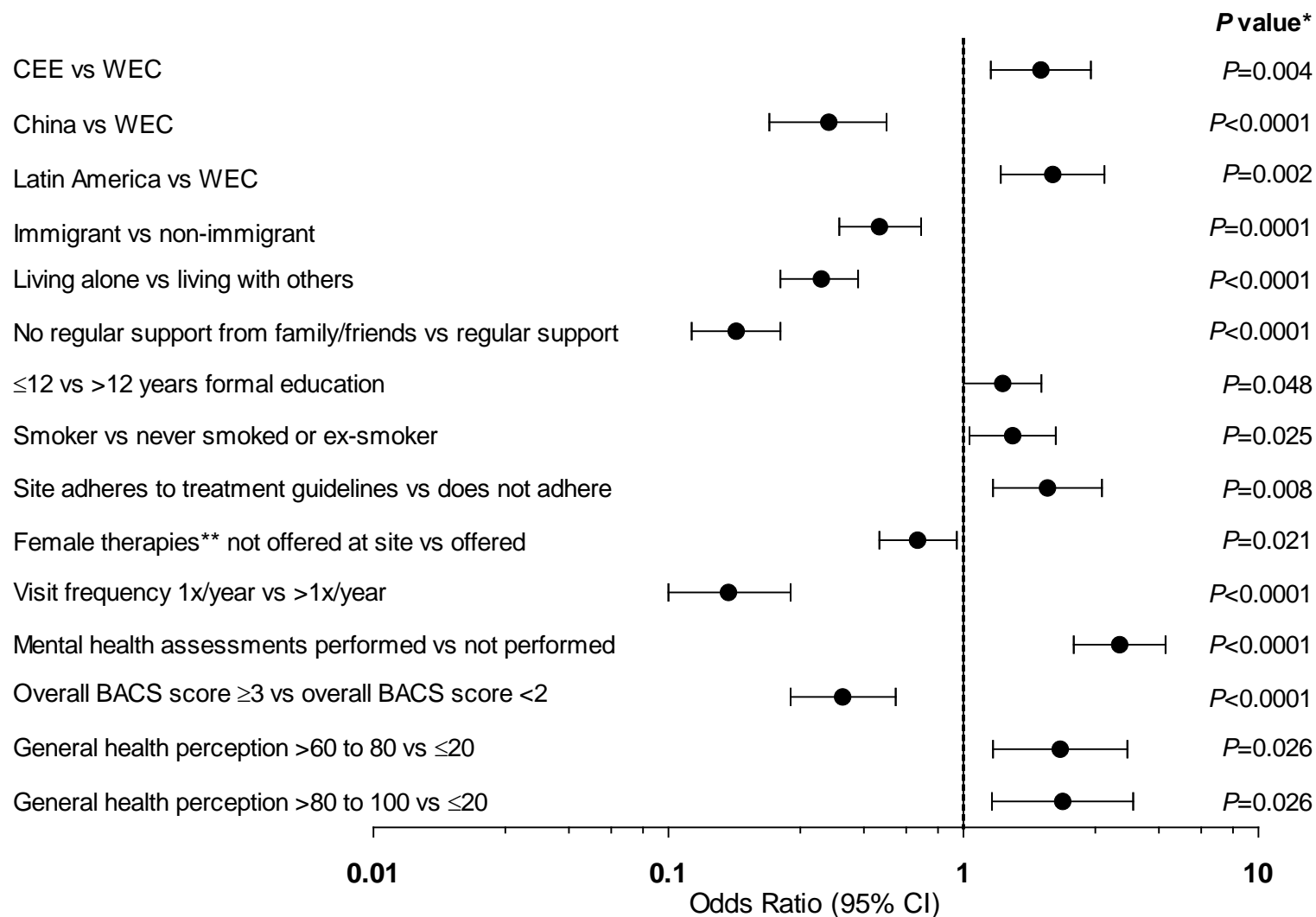
## Current Health State

$P=0.0149$



Significant differences ( $P \leq 0.03$ ) between groups were also found for trouble with attention on activities (item 7b), feeling calm and peaceful (item 7d), tired (item 7f), enough energy (item 7g), happy (item 7h), and feeling bad (item 8b)

# Factors Associated With HIV Disclosure: Univariate Analyses



\*Adjusted for multiple testing using the Benjamini & Yekutieli (2001) procedure.

\*\*Female therapies: contraceptive, mental health-related, or hormonal therapies.

# Summary and Discussion

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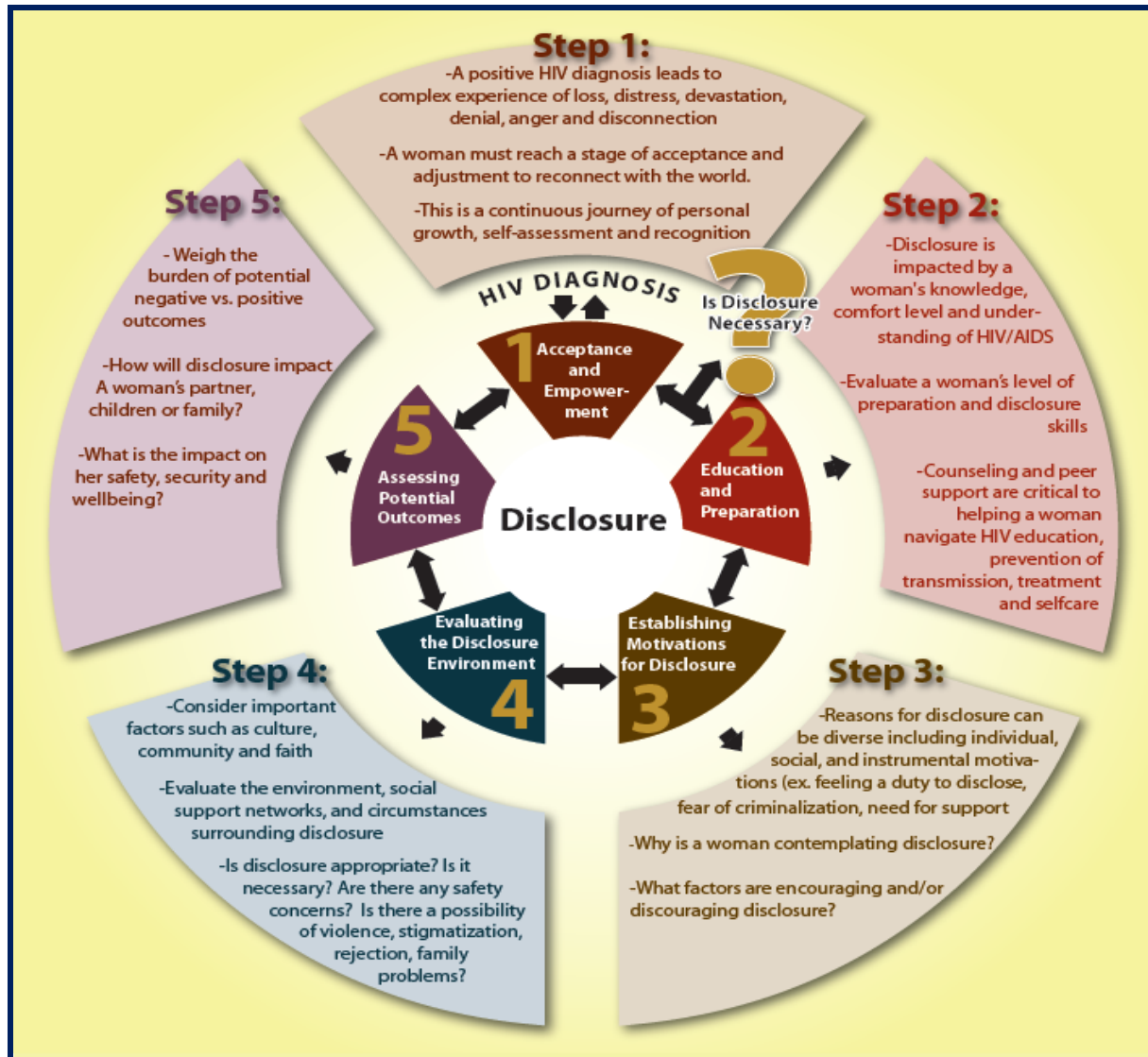
## Does disclosure lead to fewer barriers and better quality of life?

- Our study shows that there is a relationship between lower disclosure and more barriers to care and lower quality of life; although the study design does not allow us to understand the direction of the relationship
- Community stigma was consistently identified as the greatest barrier to care, regardless of disclosure status
- Women who did not disclose their HIV status outside the healthcare system reported higher barrier scores to housing, finances, supportive environment, mental health care, and transportation

## Conclusions

- Factors contributing to women's HIV non-disclosure and lack of support require further investigation to improve access to care
- As clinicians, we should consider discussing and addressing disclosure

# Possible Intervention - Disclosure Wheel



# Additional Workshop Disclosure Presentations

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*Poster viewing session 1: 21-Feb-2015 from 18:00 to 18:45*

## **Identifying Pathways for Organizational Integration of Disclosure Interventions for Women Living with HIV**

*Asiatou Barry, Women's Health in Women's Hands CHC, Canada*

## **Evaluation of HIV status disclosure among HIV positive women in rural North Central Nigeria**

*Homsuk Swomen, Institute of Human Virology-Nigeria, Nigeria*

*Poster viewing session 2: 22-Feb-2015 from 11:00 to 11:30*

## **Betwixt and Between Telling and not Telling: HIV-infection Disclosure Dilemmas among Ghanaian Women**

*Dickson Apraku, University of Education, Winneba, Ghana*

## **Using Narrative Data to Assess the Relationship between Perceived Risk and Factors Associated with Disclosure among HIV Positive Women**

*Kimberly Parker, Texas Woman's University, USA*